



Report to the Legislature

Self-Directed Care

Chapter 336, Section 9, Laws of 1999

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Executive Summary

The Self-Directed Care study was mandated by House Bill 1880, Section 9, approved during the 1999 legislative session. The University of Washington School of Nursing was asked to conduct the study and write a report in cooperation with the Department of Social and Health Services (DSHS), Department of Health (DOH) and the Governor's Committee on Disability Issues and Employment. DSHS has also included their response to the University of Washington Report and suggestions for implementing some of the report's recommendations. This report was originally due in December, 2001, but an extension was granted by the legislature in response to a request from the University of Washington and DSHS.

The Legislature has mandated that the report address the following issues:

1. Consumer satisfaction with self-directed care;
2. Service quality and consumer safety;
3. Number of personal aides who have been found to have abused or neglected consumers; and
4. Whether coercion is a factor in consumers self-directing their care or with personal aides performing self-directed care tasks.

A research team from the University of Washington School of Nursing conducted the Self-Directed Care Study, utilizing DSHS data, document reviews, consumer surveys and interviews. Section 1 addresses the state agency input to the study and details the DSHS implementation plan of the University of Washington recommendations. A summary of the University of Washington study results appears in Section 2 of this report. The University of Washington School of Nursing and DSHS Disabilities and Long Term Care Administration will post the complete University of Washington study report on the Internet.

More than 1,000 persons with disabilities registered with DSHS programs have participated in Self-Directed Care since February 1, 2000, with an average of 300 enrolled at any given time. Potentially, many more people with disabilities in the state of Washington, who are not enrolled with DSHS, also have the ability to self-direct their health-related tasks. This law allows individuals served by the private and public sectors to be able to stay in their own homes longer, where they may remain with their families and take an active part in their communities.

UW Report Findings

1. Consumer Satisfaction with Self-Directed Care

- a. There was high satisfaction with Self-Directed Care and strong endorsement for the program.

- b. People with disabilities value living in their own homes and controlling their lives and care. Self-Directed Care supports autonomy and choice.
- c. Self-Directed Care offers another alternative in service options for people with functional and health care needs.
- d. Both consumers and case managers believe that this program is preventing utilization of more expensive services (e.g. nursing homes, emergency rooms for routine care).

2. Service quality and Consumer Safety

- a. The Self-Directed Care Program was implemented with minimal logistical issues and few barriers to ongoing service.
- b. There were no negative outcomes attributable to Self-Directed Care. Benefits included improvements in quality of care and quality of life for consumers.

3. Number of Personal Aides who have been found to have abused or neglected consumers

Complaint records were examined from February 1, 2000, through July 31, 2002. During this period there were five allegations of abuse or neglect reported to Adult Protective Services (APS) for consumers enrolled in Self-Directed Care; of which two were substantiated.

4. Coercion as a factor in consumers self-directing their care or with personal aides performing self-directed care tasks

Coercion was evaluated in a number of ways, including the satisfaction survey and focused interviews. In the responses to open ended questions on the satisfaction survey, there was no indication of coercion among consumers. Among Individual Providers (IP), there was no evidence of coercion to participate in Self-Directed Care itself; however, there was an isolated report of an IP experiencing pressure to follow consumer direction that posed an occupational risk to the IP in the form of exposure to body substances without adequate protection due to consumer preference.

UW Study Recommendations

- 1. Self-Directed Care should continue to be offered and receive wider promotion among potentially eligible consumers, particularly those in communities with lower utilization rates.
- 2. Mechanisms for clinical consultation and assistance with staff recruitment and training should be more readily available for clients who prefer additional support.

3. Case managers should receive further training in program philosophy and implementation
4. Appropriate compensation for Personal Aides should be evaluated, in light of the relative costs of turnover and agency staffing.
5. Additional training should be provided on occupational risks and about the specific needs of persons with disabilities.
6. The state should explore potential expansion of Self-Directed Care to agency providers.
7. The state should further explore integration and articulation of programs such as Self-Directed Care, Nurse Delegation and Medication Assistance.
8. Further research should focus on quantifying costs and savings related to Self-Directed Care, as well as in-depth evaluation of hospitalization and facility placement prevalence and causes.

Section 1:

DSHS Comments and Recommendations

I. Self-Directed Care Background and Significance

The 1998 Washington State Legislature in House Bill 1880, Section 9, mandated this study. The data from this study are intended to inform decisions and policy making regarding self-directed care in the future and will contribute to knowledge of the impact of changes in service delivery policies in community based settings.

A. House Bill 1880

House Bill 1880, Section 9, outlined specific guidelines for the study of self-directed care, and required that the study be performed in consultation with the Governor's Committee on Disability Issues and Employment, and DSHS.

The study was required to include data, to the extent reasonably available, on the following:

- a) Consumer satisfaction with self-directed care, including consumer perception of the degree of autonomy, self-determination and choice;
- b) Service quality and consumer safety, as determined by consumers and quantifiable outcomes such as hospitalization or other facility placement;
- c) Consumer outcomes in emergency situations such as abandonment, abuse, neglect, or exploitation by individual providers (IP);
- d) Whether coercion was a factor in consumers requesting self-directed care or with IPs performing self-directed care tasks.

B. Literature Review

The philosophy of consumer direction evolved from the disability rights and independent living movement (Doty, 1998; Mahoney & Simon-Rusinowitz, 1997; Nadash, 1998; Rodwin, 1994; Simon-Rusinowitz & Hofland, 1993; Yamada, 2001). It is a philosophy and orientation to the delivery of home and community based services in which the consumers make informed choices about the services they receive including:

- ❖ Assessing their own needs
- ❖ Determining how and by whom these needs should be met
- ❖ Monitoring the quality of services received

Consumer direction is rooted in the broader concept of self-determination in which people with disabilities have overall control of their lives and an ability to participate fully in society based on four principles:

- ❖ Freedom
- ❖ Authority
- ❖ Support
- ❖ Responsibility

C. Background

The Nurse Practice Act (RCW 18.79) is a Washington law regarding the licensure of the nursing profession. This law designates sets of tasks and activities and requires that anyone performing any of those tasks for pay must be a licensed member of that profession. Nurse practice in Washington includes administration of drugs, medications and treatments, such as injections, tests and catheterizations. A licensed nurse must perform these tasks, regardless of whether the piercing of tissues is required or what degree of independent judgment and skill is required.

This state law presented a barrier to individuals with functional disabilities needing health care tasks living in their own homes. The Nurse Practice Act did not affect people who are able to perform such tasks for themselves and chose to do so, nor did the Act prohibit unpaid people from doing such tasks for another person. The Act only applied to the physical elements of the designated tasks, not the mental elements. For example, it was not acceptable for a paid unlicensed person to open a bottle of medicine, put the pill in someone's mouth, even when that individual was making all the decisions about which medication to take, when and how much.

As a result, many people who were prevented by their disabilities from physically performing necessary tasks had to obtain expensive professional assistance, ignore the law and choose to direct their paid aides in the performance of the tasks anyway, or move to a more restrictive setting where professional care was available. These barriers were first identified during the nurse delegation study completed by the University of Washington in 1998.

II. Review of DSHS Implementation of HB 1880

House Bill 1880 was signed into law in May 1999. DSHS set a target implementation date of January 1, 2000. The first self-directed care client was enrolled one month after the target date. Implementation included the following steps:

1. WAC Revisions

Self-Directed Care law was codified into the Long Term Care Services Options series, Revised Code of Washington (RCW) 74.39. 007, 74.39.050, 74.39.060, 74.39.070. Washington Administrative Code (WAC) sections revised to include self-directed care as follows:

- ❖ WAC 388-71-0105 – What definitions apply to adult protective services and the personal aide registry?
- ❖ WAC 388-71-0150 – When is the name of a personal aide placed on a registry?
- ❖ WAC 388-71-0420 – What services are not covered under Home and Community Programs?
- ❖ WAC 388-71-0580 – Self-Directed Care – Who must direct self-directed care?

2. Department Policy Development for Implementation

- ❖ Before policy was developed, a request for questions from the field was sent out to DSHS staff and contractors.
- ❖ Policy and training curriculum were developed based on many of the field questions.
- ❖ Long-Term Care Manual chapters were revised to address WAC and policy changes.
- ❖ Questions were developed for supervisors to use in monitoring self-directed care cases.
- ❖ Program management staff periodically traveled to field offices to discuss problems and answer questions. Program management staff continually answered questions and consulted with case managers and clients regarding specific self-directed care cases.

3. Training Curriculum Development

- ❖ Training curriculum was developed from input from staff and consumers of personal assistance services.
- ❖ Four individuals with disabilities from different areas of the state assisted in training staff with the independent living and consumer direction part of the Self-Directed Care curriculum. These individuals were closely affiliated with independent living programs in their local areas and active in disability issues in the state. Fourteen trainings were offered with the assistance of these individuals.
- ❖ Seven of the trainings were offered prior to implementation and seven were offered six months after implementation.
- ❖ Self-Directed Care and Independent Living training became part of the ongoing case management training for case management staff.

4. Development of Self-Directed Care (SDC) Brochure for Consumers

- ❖ The SDC Brochure was developed for a consumer audience.

- ❖ The brochure was translated into eight languages and was posted on the DSHS Internet site and was sent by mail to agencies that provide home and community-based services.
- ❖ The brochure was sent directly to approximately 24,000 DSHS clients who receive in-home personal assistance services. A toll-free number was provided to consumers to allow them to ask questions about self-directed care.

5. Development of Tracking Mechanism for Clients and Individual Providers

- ❖ The SDC law required Individual Providers (IP) who are contracted with the department to provide SDC services to be placed on a list monitored by DSHS. There was concern that without some type of mandatory tracking system there would not be accurate information about Individual Providers providing SDC.
- ❖ The Social Service Payment System (SSPS) is used to register Individual Providers. Mandatory codes were assigned to the SSPS Individual Provider Program. If the case manager did not designate whether the client was receiving SDC services, the IP would not get paid. Use of the codes was monitored against other assessment data to identify and correct mistakes.

6. Adult Protective Services (APS) Registry

- ❖ In accordance with WAC 388-71-0150 and 0155, Individual Providers under Self-Directed Care who have substantiated findings of abuse, neglect, abandonment or financial exploitation, will be placed on a self-directed care registry for Individual Providers. The information on the registry includes the Individual Provider's name, date of birth and social security number. The Individual Provider has a right to request a fair hearing up to 30 calendar days after receiving the notification letter of substantiated findings.
- ❖ This registry includes Individual Providers contracted with DSHS and those working privately. This registry is access in the DSHS Background Check Central Unit (BCCU) background check process.
- ❖ The SSPS tracking mechanism for DSHS-registered Individual Providers greatly assisted in separating out the thousands of APS complaints that did not pertain to the SDC program.
- ❖ APS modified the Adult Protective Service Automated System (APSAS) to include documentation of the alleged perpetrator's role as an individual provider of self-directed care (APSAS is not a registry).

7. Communication with the Medical Community

- ❖ The Department of Health (DOH) assisted in getting the word out to the medical community about the law.
- ❖ The Nursing Commission wrote articles to be distributed in newsletters for medical professionals. Self-Directed Care was also discussed at their quarterly meetings.
- ❖ DSHS staff fielded many questions from clinics, home health agencies and rehabilitation centers regarding self-directed care.

8. Communication with the Disability Community

- ❖ Independent Living Centers and the grass roots advocacy organization Project PAS-Port for Change wrote articles explaining how Self-Directed Care impacted the disability community.
- ❖ DSHS's Division of Developmental Disabilities and organizations such as People First and the Developmental Disabilities Council informed the DD community about Self-Directed Care.
- ❖ DSHS staff answered many questions from consumers using the DSHS toll-free hotline. Staff regularly attended disability organization quarterly meetings and held public forums to discuss SDC and any concerns the community had regarding the department's implementation process.

9. Training Development for Individual Providers

- ❖ The mandatory 22 hour "Fundamental Basics of Caregiving" was revised to add Self-Directed Care in the curriculum. This training is mandatory for Individual Providers as well as other providers of personal assistance services in a variety of settings.

10. Field Notes Sources sent to the University of Washington's Researchers

- ❖ DSHS emails, questions and requests from the field, management bulletins, SDC historical documents, implementation documents, training materials, curriculum, promotional materials, newsletters, abuse investigation documents and legislative history documents were maintained for the two-year period.

Section 2

Self-Directed Care Evaluation Study Summary

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This study evaluated Self-Directed Care, as mandated by House Bill 1880, Section 9, including evaluation of consumer satisfaction, service quality and consumer safety, instances and outcomes of consumer abuse and neglect, and whether coercion is a factor in self-directed care participation. Methods included surveys and interviews with participants in Self-Directed Care (consumers, Individual Providers, and case managers), and review of existing databases, complaint logs and reports, and field notes by DSHS staff.

A. Implementation of Self-Directed Care: Prevalence

Self-Directed Care (SDC) was initiated with House Bill 1880 in 1999. The first consumer enrolled in February 2001. Eligibility for this study included enrollment in self-directed care between February 2000 and June 30, 2001. During this period, a total of 273 consumers were identified by DSHS as being enrolled in self-directed care. Department records indicate that since June 2001, approximately 300 consumers have been enrolled in the program at any given time, with some utilizing self-directed care on a short-term basis, such as for respite or to meet a temporary need. By July 2002, this program had served a cumulative total of 1002 consumers, including five consumers funded through the DSHS Division of Developmental Disabilities. The average age of consumers on SDC was 59.0 years, with a range of 20-99 years, and 37.6% of consumers on SDC aged over 65 years.

Consumers were self-directing a variety of tasks. The most common tasks were medication administration (over 50%), and bowel and catheter care (over 20% each). Injections were also common, with a combined prevalence of over 20% when considering both insulin and other injectables. Consumers directed an average of 2.4 tasks, with a range of 0 to 8 tasks and 50% of all consumers directing more than 2 tasks. Figure 1 illustrates the percentages of self-directed tasks, comparing percentages at Time 1 (initial survey of clients between 2/1/00 and 6/30/01) and Time 2 (follow-up one year later).

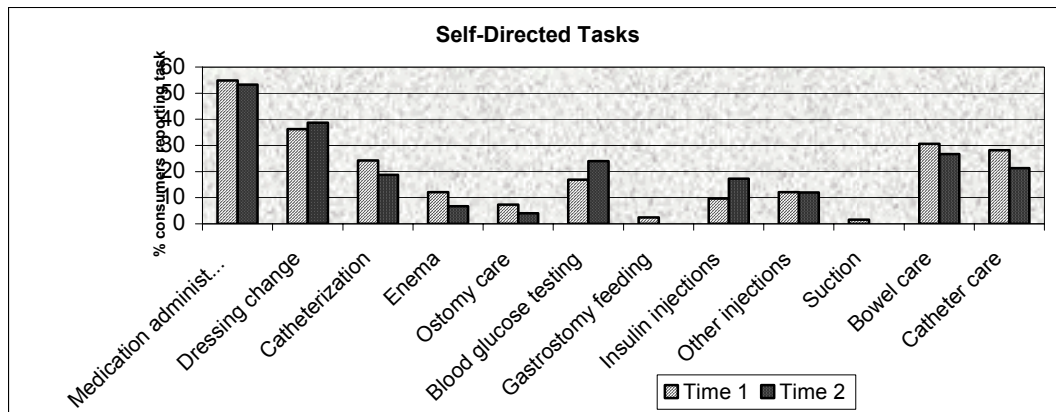


Figure 1: Self-Directed Care tasks reported by consumers

B. Consumer satisfaction with self-directed care, including consumer perception of the degree of autonomy, self-determination, and choice afforded

Consumer satisfaction with self-directed care was assessed in a variety of ways including satisfaction surveys with both quantitative measurement and open-ended questions as well as in focused interviews. In general, consumers reported high levels of satisfaction with the program, emphasizing the freedom afforded to them through self-directed care, and the opportunity to take control of important aspects of life and daily care. There was consistent evidence of improved autonomy, self-determination, and choice.

1. Satisfaction Survey

The satisfaction survey assessed general satisfaction as well as specific ratings of the degree of willingness to participate, choice in participation, safety, and perceived capability of the Individual Provider. The satisfaction survey included six questions, with response options ranging from 1 to 5, scored as 1 = very negative, 2 = moderately negative, 3 = neutral, 4 = moderately positive, and 5 = very positive. The higher the score, the more satisfied the respondent, with the highest possible score being 5. Total satisfaction was computed by summing the responses to the six questions and dividing by six to create an average score. Results for individual items and total satisfaction scores for both Time 1 and Time 2 are summarized in Figure 2. As can be seen by the average scores for each item, consumers responded very positively to all six questions, as well as a very positive average total satisfaction score.

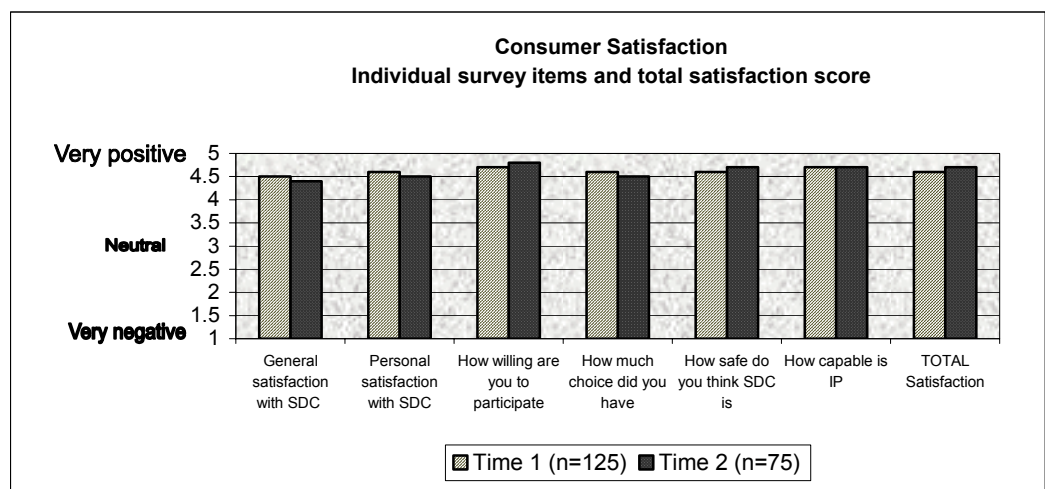


Figure 2: Satisfaction Survey: Consumer satisfaction with Self-Directed Care

Figure 3 shows the distribution of total satisfaction scores for both Time 1 and Time 2. As shown in this figure, the vast majority of consumers are

either very satisfied or moderately satisfied with Self-Directed Care (94.7% at Time 1 and 98.7% at Time 2), indicating strong endorsement for the program. Satisfaction survey results for IPs and Case Managers are in Appendix B, Figures 2-3.

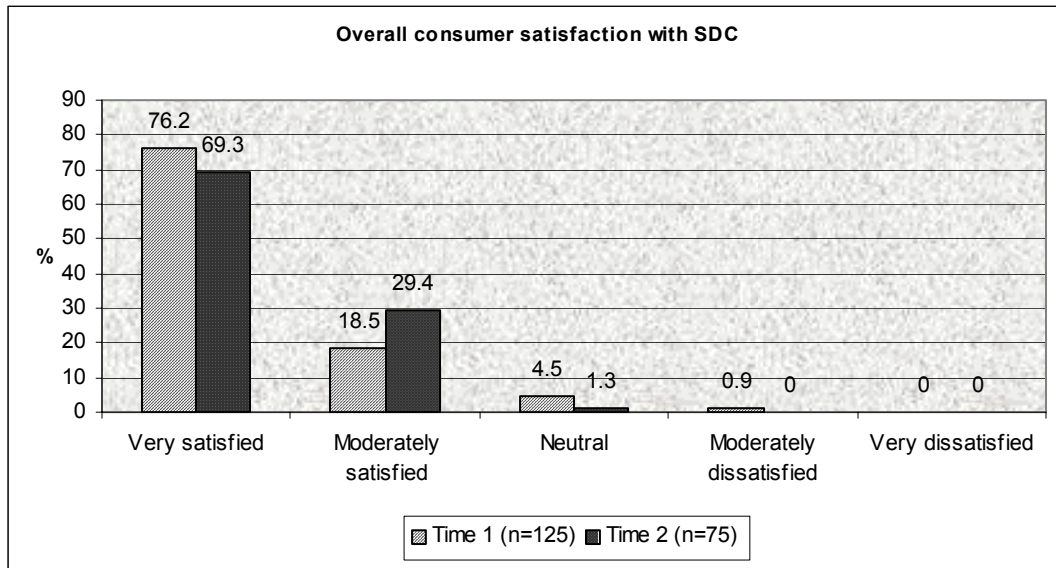


Figure 3: Satisfaction Survey: Distribution of total satisfaction scores

The satisfaction survey included open-ended questions exploring benefits, concerns, and other comments regarding self-directed care. While concerns were identified, the vast majority of comments reflected benefits. These comments are summarized in Tables 1 and 2 in descending order of prevalence, with percentage of respondents making each comment indicated in brackets.

Table 1: Satisfaction Survey: Benefits of Self-Directed Care (% making comment)

Time 1	Time 2
<ul style="list-style-type: none"> • Positive about the program (17) • Can meet needs (16) • Promotes independence, control, choice, freedom, responsibility (16) • No response (16) • Improves quality of life (11) • Can stay at home (10) • Focuses on ability, not disability (4) • Value relationship with IP (3) • Less expensive option (2) • Removes liability concerns (2) 	<ul style="list-style-type: none"> • Positive about the program (25) • Can meet needs (22) • Promotes independence, control, choice, freedom, responsibility (10) • Improves quality of life (10) • Can stay at home (10) • Value relationship with IP (9) • No response (6) • Less expensive option (5) • Provides caregiver training (2) • Relieves family members (2)

Table 2: Satisfaction Survey: Concerns about Self-Directed Care (% making comment)

Time 1	Time 2
<ul style="list-style-type: none"> • No response (44) • Non-specific concern (14) • Adequacy of payment (11) • Recruiting, hiring, retaining caregivers (8) • Case manager control/imposition (4) • Own ability to self-direct (3) 	<ul style="list-style-type: none"> • No response (44) • Non-specific concern (28) • Needs are not met (10) • Case manager control/imposition (5) • Recruiting, hiring, retaining caregivers (4)

2. Focused Interviews

The focused interviews provided in-depth information about perceptions of Self-Directed Care. Consumers identified powerful motivations to enroll in the program, primarily to be able to take charge of one's own care, to stay at home, and to meet care needs. Consumers viewed this program as providing a valued option that meets their needs in the most acceptable way, and prevents the need for nursing home placement. Consumers described their roles as directing the care and expressing one's own voice. The biggest challenge in implementing SDC was staffing, a finding that is not surprising given the general shortage of direct care providers in community based settings and the typical issues with recruitment, training, and retention that have been well-documented in nursing homes, assisted living facilities, and adult family homes. Despite the challenges of assuring adequate staffing, consumers indicated that this effort was worth it to participate in the program. Several contextual factors promoted consumer satisfaction during implementation, including convenient access to needed supplies (e.g., catheters, dressings), pharmacy support (particularly home delivery and appropriate packaging of medications), and professional support from Registered Nurses and Physicians in problem solving and assisting with training Individual Providers (IP).

The majority of consumer comments regarding satisfaction with the program reflected perceived outcomes of Self-Directed Care, in two main areas – quality of life and satisfaction with staff. These outcomes are summarized in Table 3.

Table 3: Living with Self-Directed Care: Consumer perspectives (# responses)

Quality of Life	Satisfaction with staff
<ul style="list-style-type: none"> ◆ Better timing/ability to control routine, freedom to choose (13) ◆ Better family relations (6) ◆ Get it done the way you like it (4) ◆ Get to live at home (4) ◆ Get out more (3) ◆ Stress of staffing is worth it (1) 	<ul style="list-style-type: none"> ◆ Clients are highly confident in the ability of IPs to provide care once a match has been found (20) ◆ Some experience stress over assuring consistent staff coverage (5) ◆ Value relationships with IPs (2)

Several contextual factors contributed to consumer satisfaction with outcomes of the program, including the quality of the relationship with the IP, case manager support and facilitation of the process, IP compensation, predictability of needs, and proximity of the IP to consumer affecting accessibility and travel time.

The following are quotes from consumers about the effects of Self-Directed Care on their lives:

- ◆ *“(SDC) put me in charge. I say when to do what, how to do it and you know, if you don't want to be bothered then nobody can force you to be bothered.”*
- ◆ *“Quality of life, like you know, I went to the fair this year, I hadn't been to the fair. So we took my wheelchair and that's how we went. I couldn't have done it otherwise. And it's been 2 or 3 years since we've been to a fair. And we got to go this year.”*
- ◆ *“If not for self-directed care then I have to go through a whole process of (getting a) nurse everyday to do this. It's just a lot. . .of trouble to go through. And I would be really restricted to time everyday.”*
- ◆ *“If you feel you need something done, you get it done the way you'd like it to be done... You don't have to go by, certain peoples, I guess ways of going about things, by your own. It seems to work out.”*
- ◆ *“Well I wanted help around the house, my wife would have to do all my care and it's a tremendous drain on our relationship taking from a husband/wife to a patient/nurse type of relationship...it frees my wife up to be able to be a mom to the kids getting them ready for school instead of saying no, take care of yourself. She has to get me up in the morning and you know, makes me a much happier person when my kids are taking care of their needs instead of just ME. Oh ... and it gives, you know, the opportunity to do some of the things she used to be able to do and gives me the feeling that I'm not just a drain on my family all the time...I can get on with helping out as part of the family instead of just sucking the life out of them all.”*

C. Service quality and consumer safety, as determined by consumers and quantifiable outcomes such as rate of hospitalization or other facility placement

There was no evidence of problems with quality of care or consumer safety attributable to self-directed care.

1. Quality of Care and Safety

From the perspectives of consumers, case managers, and Individual Providers, Self-Directed Care improved quality of care. Specific themes are summarized in Table 4.

Table 4: Perspectives on Quality of Care and Safety (# making comment)

Consumer	Case Manager	Individual Provider
<ul style="list-style-type: none"> ◆ Highly confident in ability of IP to perform tasks (20) ◆ Better, more complete care, right people doing the right thing at the right time (17) ◆ Feel safe (15) ◆ Expanded options for care (2) ◆ Better medication management (2) ◆ Fewer Emergency Room visits for routine care (1) ◆ Isolated incident of procedural error (1) 	<ul style="list-style-type: none"> ◆ Generally confident in IP ability to perform tasks (11) ◆ Better organized, more complete care (5) ◆ Legalizes the status quo (3) ◆ More RN training and monitoring (3) ◆ Increased choice/access (2) ◆ Concern about staff adequacy (2) ◆ Fewer ER visits for routine care (1) ◆ Better medication management (1) 	<ul style="list-style-type: none"> ◆ Confident in the directions from the client (7) ◆ Now have better training (1) ◆ Better client health and care (2) ◆ Better medication management (1) ◆ Not enough time allowed (1)

For consumers, improvements in care were recognized as an expansion of options, a more comprehensive approach to care, better individualization of care (timing and tailoring to personal need), and improved medication management. In several cases, Self-Directed Care replaced more costly and inconvenient visits to Emergency Rooms for routine care. One consumer described a procedural error, attributed to his own supervision.

Case Managers also supported the impression that Self-Directed Care promotes better-organized and more comprehensive care. Many expressed relief that this program has legalized the status quo, and addressed a gap in service that was being filled in unauthorized ways by individuals attempting to meet their needs in a system that did not provide for such customization. Case managers concurred with the impression of consumers that Self-Directed Care has improved medication management and contributes to lowered use of Emergency Rooms for routine care. Case managers expressed awareness of the challenges with staffing and recognized the significance of adequate staffing to the success of the program for an individual. Finally, Individual Providers expressed confidence in the ability of consumers to direct them, and appreciated the additional training that the program has provided for them.

The vast majority of consumers indicated that they felt safe with Self-Directed Care, and Individual Providers expressed feeling safe because the consumer was directing the care. Interestingly, when asked about safety, both consumers and Individual Providers identified issues unrelated to

Self-Directed Care itself, including fire safety (alarms, extinguishers, evacuation plans), transferring (falling or causing IP back injury), crime, and accessibility of help in an emergency.

2. Hospitalization and other facility placement

Of the thirty clients interviewed, fifteen reported inpatient hospitalizations in the previous year. None of the hospitalizations reported could be directly attributed to the Self-Directed Care Program, and likely reflect an expected pattern of utilization. Reasons reported for the hospitalizations included recurrent urinary tract infections, multi-system health problems, myocardial infarctions, pneumonia, fractured hip, skin grafts, toe amputation, insertion of a suprapubic catheter, and elective rehabilitative surgeries. Three additional clients reported multiple emergency room visits for urinary tract infections and catheter maintenance procedures. These types of hospital utilization are common in older adults and people living with disabilities in institutional settings where professional care is available as well as those living with chronic conditions at home. One client reported repeated emergency room visits before starting self-directed care for administration of injections of medications for MS. After starting SDC, these visits were no longer required. Due to the limitations of the study, extensive health care utilization patterns prior to and after initiation of the program, as they relate to underlying health conditions, were not examined.

The Self-Directed Care Program offers another alternative for consumers and case managers as they evaluate optimal services. Both consumers and case managers reported that this program enables consumers to meet skilled needs at home more effectively, relieving burden on the family, and enabling continued residence in the preferred location. Case managers reported that they were actively using Self-Directed Care as an alternative to nursing home placement, and in some instances, had been able to arrange quicker discharge from nursing homes to home because of Self-Directed Care.

3. Case Study

This case study illustrates the potential of the program to meet the needs of a highly motivated individual with considerable knowledge of her condition and her needs. The following are direct quotes from a consumer, Individual Provider, and case manager regarding a specific instance of Self-Directed Care.

Consumer:

“One of the things is I can keep my fluid under control better. I don't have to wear a catheter 24-hours a day, 7 days a week for a month at a time. It can be worn when my

fluid is up and if I watch real carefully, usually I can keep it down to where it doesn't get too bad. Sometimes if there is an infection or my fluid, my heart it will build, but now I can, I'm more comfortable at home, I'm getting, to be able to get around better. The problem is I can't get my catheterization supplies approved all the time, that's kind of a drawback on it, but doing the things at home, giving my shots at home, I have more freedom, I have more better quality of life, I'm not spending hours in the emergency room or weeks in the hospital. It takes 10 minutes to take 100 milligrams of Lasix in the hip and catheterize, 10 minutes at the top. Very quickly the fluid starts going off. If you go to the emergency room, you're liable to be there for 3 to 4 hours before you can be seen and then it's another 1 to 2 hours you're in there and then they want to watch you for awhile and then you're tired and you're wore out. If the person personally knows their own body, their own needs and has the education to know what they need and how to control it, it's more convenient at home, it's more economical at home. For one trip to the emergency room can be from \$600 to \$1000. You've got a person that comes in, takes her 10 or 15 minutes to do that job and if it needs to be done every so often it's easier to do it than having to get out, I mean you've got more mobility, you've got more freedom and more control, more control over your own life plus what's being done to you.”

Individual Provider:

“We live in a very conservative, backwards area. Her pain management, which she can now take care of herself, she's not in as much pain, her quality of life is better, she can get up a little more, she can think a little clearer, she's not so grouchy, I mean her disposition has improved thousands of times. She knows when she needs to be cathed, because she can feel the fluid build up on her lungs and her breathing and instead of somebody else going I think it's a good time to cath you now, she could have told me the day before it's gotten too far. Honey I need it now. And you know, that makes her mobility a lot better. It makes her disposition a lot better. It's kind of, with her size and things it's hard for her to transfer to different places and there's very few things that I can't do at home for her. So that makes, you know, she's in better health, she's in better spirits. They didn't expect her to live this long let alone as long as she has. So yeah, I see a lot of benefits.”

Case Manager:

“When she was getting what she needed without any problems with Medicaid the self-directed care was going great and actually that part is going great because it was reducing the amount of times that she had to go the emergency room to ... generally she'd go several times a month ... basically just to go to have them tell her we've got to cath you again, sit here for 6 hours, uncomfortable for her, very, she's got some depression just from everything that's gone on, so that just made her feel even worse and she, you know, it's worked out a lot better where she can just have this done in the comfort of her own home and it's cheaper in the long run for Medicaid. So she's really liked that. I think it's made her feel a little bit more in control of some things of her life and her care. So the self-directed care part has been great. It's just getting what she needs to do it and that's a Medicaid issue.”

D. Number of Individual Providers who have been found to have abused or neglected consumers

Complaint records were examined from February 1, 2000 through July 31, 2002. During this period, five allegations of abuse, financial exploitation or neglect were reported to Adult Protective Services (APS) for consumers enrolled in Self-Directed Care; two were substantiated. In comparison, during the two year period July 2000 – July 2002, APS conducted 18,417 investigations involving allegations of abuse, abandonment, financial exploitation, neglect or self-neglect of vulnerable adults; at least one allegation was substantiated in 4,070 (22%) of the investigations. Complaints involving self-directed care consumers formed a very small subset of all complaints investigated by APS. Five allegations of abuse or neglect for 1002 persons self-directing care reflects a 0.49% rate of reporting, and a 0.20% rate of substantiated abuse or neglect for enrollees in Self-Directed Care.

Specifics of the allegations follow:

- ◆ Physical abuse by a live-in Individual Provider. This allegation was substantiated and the Individual Provider contract was terminated immediately.
- ◆ Neglect related to reporting to work under the influence of alcohol (odor on breath) and lack of responsiveness to the calls of the consumer while on duty. This allegation was substantiated and the Individual Provider contract was terminated.
- ◆ Neglect-exploitation (missing medications). This allegation was investigated and the case was closed as undetermined.
- ◆ Exploitation (financial). This allegation was investigated and closed with a finding of insufficient evidence.
- ◆ Neglect-exploitation (medication diversion). This allegation was investigated and closed with a finding of insufficient evidence.

E. Consumer outcomes in emergency situations such as abandonment, abuse, neglect, or exploitation by Individual Provider

In the substantiated case of physical abuse, the APS caseworker immediately reported the incident to law enforcement, which responded and made no arrest. The Individual Provider's contract was terminated. Since the Individual Provider (IP) lived in the home with the consumer, the caseworker made sure the consumer had safe alternative lodging, made referrals to a domestic violence shelter, offered assistance in obtaining a protection order (which was declined), facilitated help for the consumer from the Area Agency on Aging in finding a new caregiver and provided assistance in installing a Lifeline in the home. Follow-up visits were made to monitor that the IP had moved out of the home and the caseworker noted that the condition of the home after contracting with the new IP was significantly improved.

In the substantiated case of neglect related to alcohol use, the Individual Provider contract was terminated without any negative outcomes for the client.

F. Whether coercion is a factor in consumers requesting self-directed care, or with Individual Providers performing self-directed care tasks.

Coercion was evaluated in a number of ways, including the satisfaction survey and focused interviews. The satisfaction survey included a specific item that asked whether the individual had a choice in deciding to participate in self-directed care. As can be seen in Figure 4, the majority of both consumers and Individual Providers perceived that they had a choice in deciding to participate in Self-Directed Care. In the responses to the open ended questions on the satisfaction survey, there was no indication of coercion.

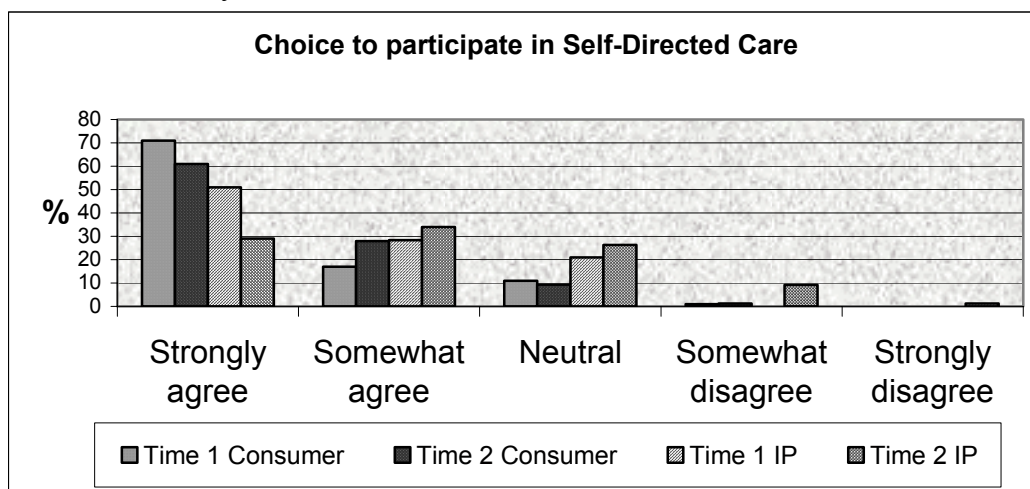


Figure 4: Choice to participate in SDC for Consumers and Individual Providers

The focused interviews specifically explored whether coercion was a factor in participating in Self-Directed Care. There was no evidence of coercion among consumers. Among Individual Providers, there was no evidence of coercion to participate in Self-Directed Care itself; however, there was an isolated report of

an IP experiencing pressure to follow consumer direction that posed an occupational risk to the IP in the form of exposure to body substances without adequate protection due to consumer preference. In the focused interviews, there was also an isolated report by a case manager who was experiencing pressure to implement the program from a DSHS supervisor.

G. Additional Findings

Additional findings of this study can be grouped into three main areas: 1) The process of self-directed care, 2) Staffing issues, and 3) Case manager and DSHS issues. An overview of the findings follows.

1. The process of self-directed care

Efforts to launch this program by DSHS were impressive, with a proactive approach to developing protocols and training materials and extensive attention to disseminating information and providing technical assistance. Field notes substantiated a comprehensive process. It should be noted that participants reported few logistical issues, and the program was perceived as being accessible and understandable by most.

A number of factors influenced initiation of Self-Directed Care for a particular consumer, including the quality and timing of information made available to both the consumer and to case managers, particularly during early implementation. Promotion of the program, both at the state and local agency levels, played a role in awareness and interest in pursuing this option. While most case managers were supportive of the program, there was a range of beliefs and values about the program and perceptions of the capacity of consumers to self-direct. Some case managers had particularly high caseloads, or had taken on new assignments and did not yet know all their clients well enough to recommend Self-Directed Care extensively.

2. Staffing issues

It is well known that recruitment and retention of direct care providers in community based long term care is a growing concern, with a shrinking labor pool, high turnover, and alternative employment opportunities that provide better pay and working conditions. While not attributable to Self-Directed Care *per se*, similar to findings in nursing homes, assisted living facilities, and adult family homes, staffing issues were significant for the Self-Directed Care Program.

Consumers reported that Self-Directed Care requires adequate, competent staff, and active management of the process of getting staff (recruiting/selection), keeping staff (retention), training staff, and supervising/monitoring staff. Consumers valued their relationships with their Individual Providers and were highly motivated to assure ongoing coverage. There was a range of need for staff, with some consumers

having intermittent or circumscribed needs (such as catheter irrigation or dressing changes), and others requiring more extensive staff coverage (frequent medications and assistance with activities of daily living). Hence some consumers were working with one Individual Provider, and others were managing several staff, with the added complexity of hiring, supervising and training. Some consumers had longstanding relationships with their care providers, while others were newly recruiting. The available labor pool was a barrier for some, particularly in rural areas. Consumers expressed frustration with the compensation they were able to offer Individual Providers, recognizing the value of rewarding and retaining qualified staff.

Consumers recruited staff from a variety of sources, including referral by a friend or family member, referral by case manager or agency, and less commonly, by advertising. Most consumers provided the individual training themselves, with some involving professionals (RNs, Home Health, Physicians, and Rehabilitation therapists) in augmenting the instruction. Ongoing issues of supervision included retaining competent staff, finding relief and covering for absences, coordinating caregiver schedules, and personnel management.

Individual Providers expressed both rewards and challenges with their work. The vast majority expressed high satisfaction with the Self-Directed Care program, and identified several features of this program that make it particularly attractive for workers. Most importantly, Individual Providers valued and enjoyed their jobs, felt good about being able to help, and valued their relationships with their clients. They preferred working in the home, particularly compared to nursing home work, and appreciated having more one-on-one time.

Individual Providers were challenged by a number of factors, including emotional stress, work hours, compensation, and occupational risks. Emotional stressors included a feeling of unrelieved responsibility, the emotional toll of providing care, interpersonal frustration, and burnout. Work hour issues included being on call, having difficulty finding respite or temporary relief, and feeling obligated to donate time when a visit exceeded the time that was authorized in the service plan due to unpredictable needs. Both Individual Providers and consumers viewed compensation as inadequate, with low hourly pay rates and a lack of benefits (health care coverage, disability insurance, travel time/mileage reimbursement, Labor and Industry insurance). Some reported frustration over logistical problems with payroll processing. Finally, some Individual Providers raised concerns about occupational risks for injury during heavy lifting and transferring and for body substance exposure with inadequate protection. The vast majority of Individual Providers talked about

respecting the point of view of the consumer and accepting their direction, reflecting a good understanding of the intent of the program.

Most case managers were confident in the ability of staff to provide quality care, but some had reservations due to perceived variability in ability and to difficulties in finding and retaining competent caregivers. Case managers had differences of opinion about the extent of their role in assuring competent staff, ranging from viewing the issue as the complete responsibility of the client, to assuring that IPs are trained and offering ongoing review and support. Case managers were involved in procuring background checks and in processing payroll for IPs. In general, case managers recognized that the consumer held responsibility for hiring and evaluating staff.

3. Case manager and DSHS issues

Case managers were motivated to implement Self-Directed Care by several factors including supporting the desires of consumers, supporting consumers to stay at home, and recognizing and respecting the capacity of consumers to decide and direct their own care. Leadership at both the state and local levels made a difference in promoting the program and in applying the training that was provided to all case managers in the State.

There was a range in the degree to which case managers had internalized the philosophical underpinnings and assumptions of the program. While most fully endorsed Independent Living goals, some had reservations and expressed concern about the ability of certain consumers to direct their own care. In some cases, there was a tension between the case manager and the consumer's view on the ability to self-direct, reflecting different orientations and a parental point of view on the part of professionals. While health care tasks are a part of life for the person with disabilities, some professionals make distinctions that are artificial to the person on services. This potentially results in a tendency to medicalize, compartmentalize, and intrude upon daily living freedoms that would not be tolerated by those without disabilities.

Particular questions that arose for these case managers included clarification of their role in assessing ongoing ability of a consumer to self-direct, how to deal with fluctuating abilities, and confusion about their options for problem solving these areas of concern. Several indicated that follow-up training now that they had some experience would be of benefit.

Case managers recognized core responsibilities, including providing information and developing, managing and monitoring the service plan. Beyond these activities, case managers described a range of perceptions of their role in Self-Directed Care, from a very limited role, to taking an active role in promoting the program and facilitating access to staff.

Likewise, consumers and Individual Providers had a range of expectations and desire for case manager involvement, with some desiring little contact and others wishing for more support and assistance. When expectations of consumers, case managers, and Individual Providers were in alignment, the relationships were most positive.

Within the DSHS's Division of Developmental Disabilities (DDD), only five individuals were enrolled in the program from initial implementation through July 31, 2002, due to limited applicability of The Self-Directed Care Program to clients of DDD. Several factors contribute to this pattern, including the eligibility criteria that consumers have the cognitive ability to direct their own care and that consumers be over 18 years of age, criteria that are not met by a significant number of consumers in DDD. Another substantial sub-group receives care from agency providers who are not eligible to participate. Staff in DDD suggested that the program could be expanded to include agency providers. All participants were asked for their suggestions to DSHS and DDD. There was an overwhelming desire by all participants to continue the program.

II. CONCLUSIONS

This study evaluated Self-Directed Care during the first two and a half years of implementation using a variety of methods and data sources. To date, this program has served over 1000 consumers in Washington State with no apparent negative outcomes and high satisfaction among participants. Significant findings of this evaluation include:

- ◆ Consumers, case managers, and Individual Providers have reported no negative outcomes. Reports of abuse and neglect were rare, were not directly attributable to Self-Directed Care, and were addressed appropriately. A variety of benefits have been described, including improvements in quality of life and quality of care for consumers.
- ◆ All participants report high satisfaction with Self-Directed Care. In both survey and open-ended interviews, participants expressed strong endorsement for the program.
- ◆ People value staying at home and want to have control over their lives and care. Self-directed care supports autonomy and choice, enabling consumers to have more control over their daily routines and life, assuring that care is delivered when and how it is desired by the consumer.
- ◆ Self-Directed Care offers another alternative in the array of options for persons with functional and health needs. The Self-Directed Care program meets the goals of consumers who are highly motivated to stay at home and desire to manage their own care.

- ◆ Self-Directed Care legitimizes and acknowledges the full scope of needs and has enabled case managers to develop more comprehensive and inclusive service plans.
- ◆ Both consumers and case managers believe that this program is preventing utilization of more expensive services (e.g., nursing homes, Emergency Rooms for routine care). It is difficult to quantify cost outcomes – this program provides more care of a certain type and has the potential to prevent higher cost utilization.
- ◆ The Self-Directed Care Program was well implemented – participants identified minimal logistical issues, and there were few barriers to ongoing service once a consumer enrolled in the program. There is variability in how self-directed care is implemented, based on consumer preferences and condition/ needs as well as caregiver characteristics. There is a range of preferences for the amount of external support desired by consumers, with some wanting little involvement by outside agencies and others welcoming support.
- ◆ The biggest challenge to implementation, assuring adequate staffing, is not directly attributable to the Self-Directed Care program, but is a reflection of a broader labor issue affecting consumers in all long term care settings. There are significant issues in the working conditions for Individual Providers including compensation, occupational exposures (e.g., lifting, body substance exposure, emotional stress), and working hours (i.e., predictability, on-call status, availability of relief).

III. IMPLICATIONS AND RECOMMENDATIONS

This evaluation supports continuing the Self-Directed Care program, and identifies several issues that warrant further discussion and potential resolution. Implications and recommendations from this study include the following:

- ◆ Self-Directed Care is a program that enhances consumer choice and autonomy, promotes individualized service delivery respectful of consumer preferences, and has the potential to reduce utilization of higher cost services. It is recommended that this program continue to be offered, and receive wider promotion among potentially eligible consumers, particularly in communities with lower utilization.
- ◆ There is a range of consumer desire for external support, with some wanting no intervention beyond authorizing payment, and others desiring more frequent and intense consultation and advice from case managers and Registered Nurses, primarily for assistance with health condition problem solving and assistance with staff recruitment and training. Consumers are most satisfied when there is a match between their desire for support and the support that is available. It is recommended that mechanisms for clinical

consultation and assistance with staff recruitment and training be available for consumers who desire such support.

- ◆ Case managers requested further training in program philosophy and implementation, with particular attention to concerns raised about consumer ability to direct care and potential approaches to problem solving issues of fluctuating ability as they arise.
- ◆ Staffing is a critical element of Self-Directed Care. A number of issues in working conditions for Individual Providers were identified, similar to direct care providers in other settings. It is recommended that appropriate compensation continue to be evaluated, with consideration of the relative costs of turnover and agency staffing. Individual Providers requested more specific training and problem-solving about occupational risk (e.g., body mechanics, body substance protection) and about the specific care needs of persons with disabilities (e.g., common disabling conditions and care approaches).
- ◆ Based on experience to date, it would be appropriate to explore and evaluate potential expansion of Self-Directed Care to agency providers.
- ◆ A number of innovative programs have been launched in Washington State, with varying eligibility criteria and target populations. These include Self-Directed Care, Nurse Delegation, and Medication Assistance. Self-Directed Services are currently being explored within DDD. As these programs mature and serve more consumers, it would be worthwhile to explore integration and articulation of these programs across the continuum of community residences and situations to promote optimal utilization. A related assessment would include ongoing review and identification of regulatory and reimbursement barriers to home care.
- ◆ Based on preliminary findings of cost savings related to prevention of higher cost utilization, further exploration is warranted. Evaluation of actual cost and utilization outcomes was beyond the scope of this study. It is recommended that further research focus on quantifying costs and savings related to Self-Directed Care, as well as in-depth evaluation of hospitalization and facility placement prevalence and causes.

IV. STUDY PARAMETERS

Methods were selected to incorporate multiple sources of data and several methodological approaches, offering the most effective and feasible design strategy for completing the evaluation mandated by House Bill 1880. It was assumed that it was not possible to describe “cause and effect,” nor was it realistic to expect findings that were completely representative and generalizable. Rather than conclusions that are “generalizable” to every situation, this study has provided in-depth knowledge about a range of findings based on the current context.

The study findings reflect the perspectives of those who were willing to participate. Every attempt was made to include as many participants as possible. While an unusually high proportion of consumers participated, both case managers and Individual Providers were less well represented. While demographic comparisons of consumers who declined to participate indicated no significant differences from those who did, little else is known about those who refused to be a part of the study. In an effort to overcome simple refusals to participate, multiple opportunities to provide input were made available, including review of all calls to complaint or inquiry hot-lines, inclusion of all comments made in writing to the department, and inclusion of all comments made in public meetings. By using multiple methods and data sets, the design addressed the limitation of participation. The health care utilization data that was available through standardized databases provided minimal insight into the causes behind hospitalization or nursing home placement, limiting conclusions regarding the effects of Self-Directed Care on these outcomes.

Section 3:

DSHS Implementation of Study Recommendations

DSHS concurs with the University's recommendations referenced in Section 2. DSHS will take the following steps to promote and follow the report recommendations, as are possible with current budget and programmatic constraints.

DSHS staff will concentrate in the next year on promoting self-directed care in communities with low utilization. This will be done in cooperation with the Governor's Committee on Disability Issues and Employment, Independent Living Centers, Governor's Office of Indian Affairs, Developmental Disabilities Council, Pas Port for Change and other disability-based organizations. Translated versions of the Self-Directed Care Brochure will be sent to agencies that work with ethnic and cultural communities where there is low enrollment. Trainings will be scheduled in these communities during the next two years to increase awareness about Self-Directed Care.

DSHS will enhance the availability of alternative methods for accomplishing health-related tasks when desired by consumers. If an individual cannot or does not want to self-direct his care, or the individual's health status changes dramatically and the individual no longer wants to self-direct, other options are limited and expensive. DSHS, DOH, the Nursing Commission, home health agencies and home care agencies are working on legislation to expand nurse delegation into the home setting, which may provide alternatives for consumers in these situations.

DSHS will explore incorporating parts of its existing case management training into a separate training for individual providers and consumers. During the two years of the study, DSHS case management training was modified to include aspects of self-directed care and independent living philosophy. Case management training is offered on a regular basis throughout the year. This training explores ways case management staff can encourage choice and control for consumers receiving personal assistance services. Problem solving is addressed throughout this five-day training for case management staff. This new self-directed care training could be incorporated as a class offering for the 10-hour continuing education requirement for all providers.

DSHS will be working closely with the newly established Home Care Quality Authority to address individual provider recruitment and retention issues. Recruitment and retention of individual providers is a critical element of self-directed care. DSHS has attempted to address these issues with the Personal Assistance Recruitment and Retention (PARR) grant that supports two small pilot projects. There has been initial success with the PARR pilot projects, but the efforts are geographically limited to Snohomish and Spokane counties. The issue of adequate compensation and benefits still needs to be addressed. DSHS will be

working closely with the newly established Home Care Quality Authority to address these issues in the future.

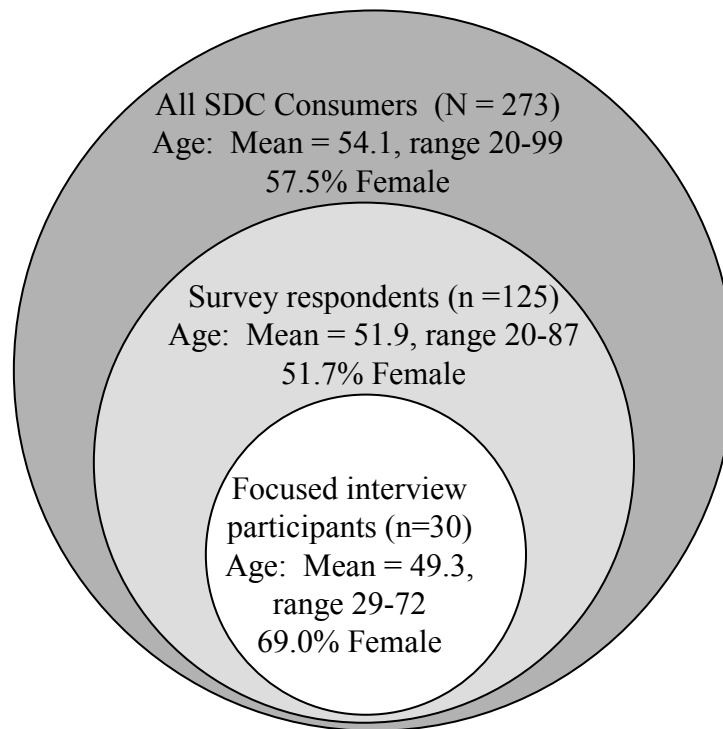
DSHS will conduct a series of focus groups and meetings to explore and evaluate the potential for expansion of self-directed care to agency providers with assistance from consumers and home care agencies. Currently, DSHS is working with the National Association of State Units on Aging (NASUA) and the Home and Community Based Services (HCBS) Network to utilize the Consumer Direction Tool. This tool was developed collaboratively by NASUA and the HCBS network to assist consumers and policy makers in determining how home and community based service programs offer consumers opportunities in choices and directing their services. DSHS will use this tool to identify if there is support for the idea of expanding self-directed care to home care agencies.

DSHS will explore expanding ongoing coordination of care efforts to include self-directed care. Currently, DSHS is working to on integration of acute and long-term care services through coordination of care. One of the populations that have been identified in this project includes individuals with quadriplegia, multiple sclerosis, ALS, and decubitus ulcers. Adding the coordination of self-directed care may be a viable option as many of the clients identified in the project may already be self-directing their care.

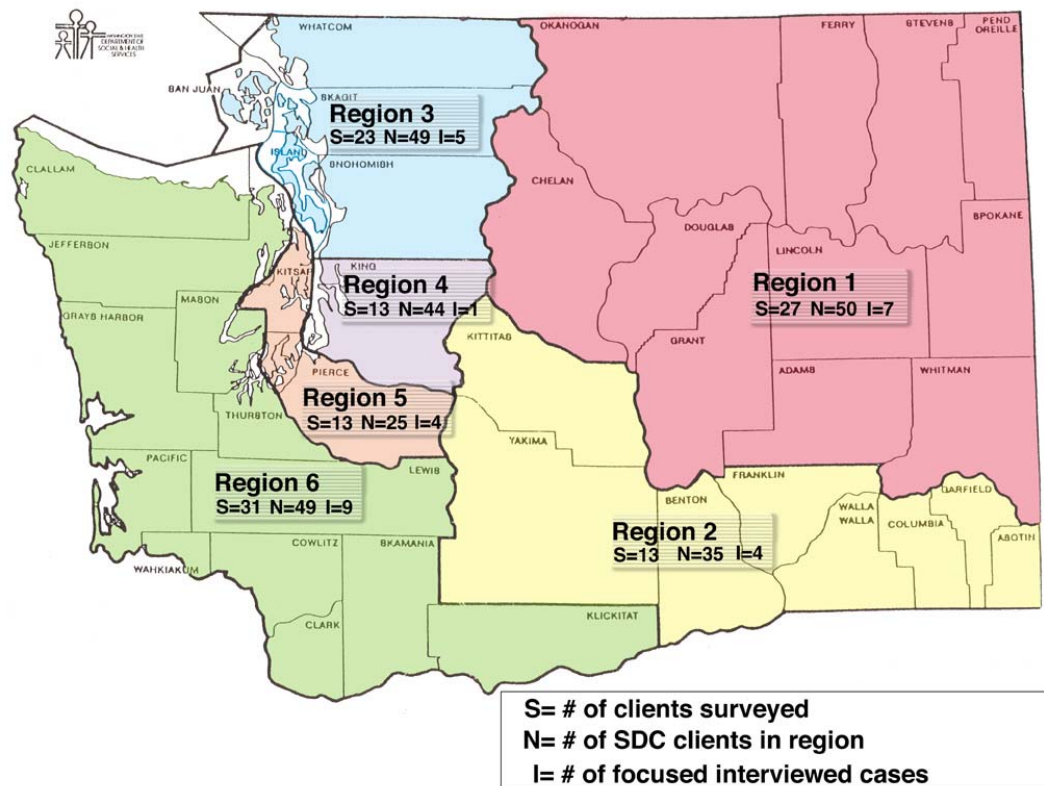
APPENDICES

Appendix A: Data sets and Samples

Data Set	Sample and sample sizes
Satisfaction Survey	Time 1: 125 Consumers, 29 Case Managers, 69 Independent Providers Time 2: 75 Consumers, 65 Case Managers, 76 Independent Providers
Focused interviews	84 in-depth interviews with: 30 Consumers 30 Independent Providers 24 Case Managers representing 28 of the consumers
Incident reports/Hot-line complaints	5 allegations during study period Review of initial complaint and follow-up documentation by departments
MMIS and Comprehensive Assessment data	Obtained for 273 consumers enrolled in Self-directed care during study period
Field notes	Total of 383 documents reviewed: Training notes and materials, technical support notes, meeting minutes, e-mail/questions from the field, background reports, legislative history documents, implementation documents

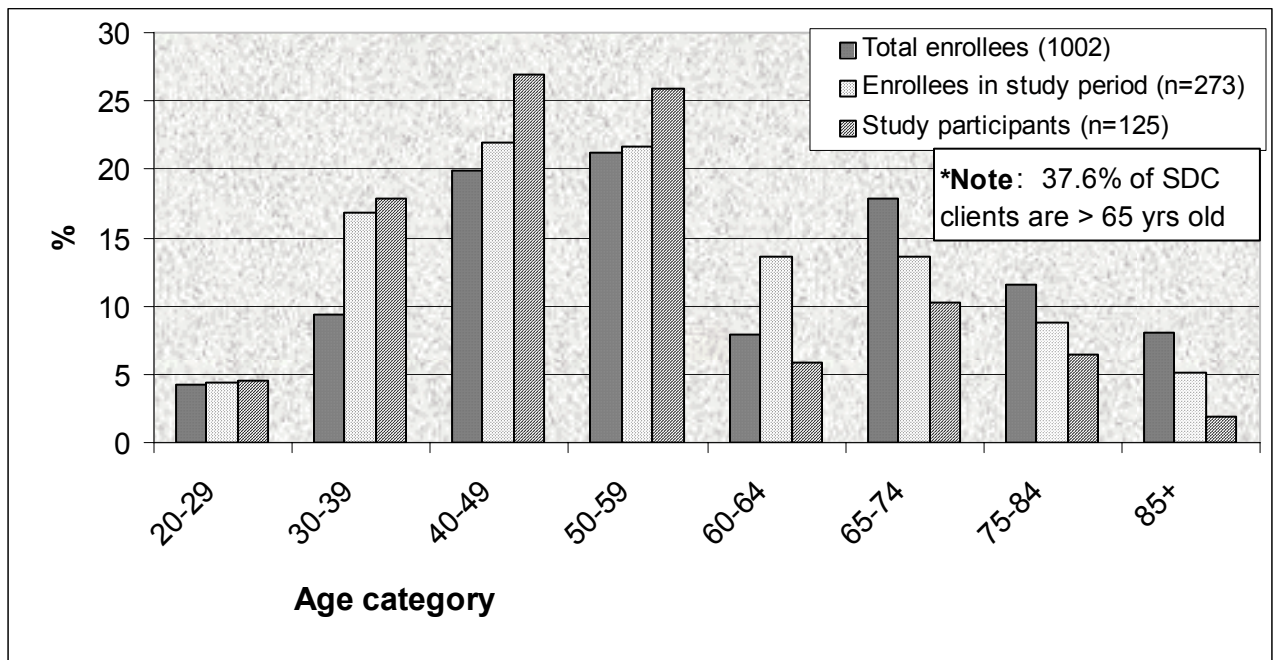


Appendix B. Consumer samples



Appendix C: Regional representation of consumers

Appendix D: Age distribution for Self-Directed Care consumers and study participants



Appendix E: Demographic characteristics of survey respondents

	Case Manager	Consumer	Independent provider
Sample size	29	125	69
Age (mean, SD, range)	44.8 (9.8) 27 – 62	51.9 (14.7) 20-87	43.7 (13.1) 18-80
Gender (% F)	78.6	51.7	82.9
Ethnicity			
African American		2.4	4.3
Hispanic	3.4	1.7	1.4
Native American		4	4.3
Asian/Islander	10.3	1.6	2.9
Caucasian	82.8	83.9	67.1
Other		2.4	1.4
Declined to answer	3.4	5.6	18.6